

FACTORS RELATED TO PARENT PROVISION OF
SEXUALITY EDUCATION FOR YOUTH
WITH ASPERGER'S DISORDER AND
HIGH FUNCTIONING AUTISM

by

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ABSTRACT

This study examined the relationship between autism spectrum disorder (ASD) symptoms, parental romantic expectations, and parental provision of sexuality education in a sample of 120 parents of youth aged 12-18 years who were diagnosed with ASD by a healthcare professional. Regression analyses showed that overall ASD symptoms predicted parental romantic expectations, but did not predict parental provision of sexuality education. Secondary analyses using simple linear regression showed that specific ASD symptoms (i.e., social motivation and social cognition) predicted a small amount of variance in parental provision of sex education. Additionally, exploratory regression analyses identified other factors related to parent provision of sex education for youth with ASD. Parents who rated themselves as more effective regarding their ability to communicate with their children about sexuality and parents who rated themselves as more prepared to manage their child's sexual development covered a greater number of sexuality-related topics with their child. The results of the current study have implications for the development of interventions to promote effective sexuality communication and positive sexual health outcomes for youth with ASD.

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INTRODUCTION

Definition of Autism Spectrum Disorders

Autistic disorder and Asperger's disorder (collectively referred to as Autism Spectrum Disorders, or ASDs) are pervasive developmental disorders that affect up to 1 in 88 children in the United States (Centers for Disease Control and Prevention, 2012), with males affected more frequently than females at a ratio of approximately 4:1 (Fombonne, 2005). The primary deficits that characterize autistic disorder are (a) severe and sustained impairments in social interaction; (b) deficits in communication skills; and (c) stereotyped behavior, activities, and/or interests (American Psychiatric Association, 2000). In addition to these primary diagnostic symptoms, cognitive and intellectual functioning is impaired in an estimated 62% of individuals with autism, with presentation ranging from "high functioning autism" (HFA), characterized by average to superior cognitive functioning, to "low functioning autism" (LFA), which is characterized by mildly to profoundly impaired intellectual functioning and verbal communication (Centers for Disease Control and Prevention, 2012). A diagnosis of Asperger's disorder (AD) is given when a person presents with deficits in social interaction and stereotyped behavior, activity, and/or interests (criteria #1 and #3 above) but without the presence of clinically significant delays in language, cognitive development, age-appropriate self-care skills, adaptive behavior (other than social interaction), or curiosity about the social

environment (American Psychiatric Association, 2000). Although there is some debate about whether HFA and AD should be considered diagnostically distinct disorders (Gillberg, 1998), research indicates that individuals with HFA and AD have similar profiles of intellectual functioning and similar executive functioning abilities (Ozonoff, South, & Miller, 2000). In addition, Ozonoff and colleagues (2000) found no differences between children with HFA and AD on specific ASD symptoms (e.g., reciprocal social interaction, communication, or repetitive behaviors/stereotyped patterns). Accordingly, the fifth edition of the *Diagnostic and Statistical Manual* collapsed autism and Asperger's disorder into a single diagnostic category referred to as autism spectrum disorder (American Psychiatric Association, 2013).

Primary Deficits

Individuals with an ASD show social skills deficits across several areas that lead to difficulty initiating and regulating social interaction and failure to develop peer relationships at an appropriate developmental level. One of the primary social difficulties observed in ASD is difficulty in using and understanding nonverbal behaviors (e.g., eye-to-eye gaze), to decode facial expressions, and to understand nonverbal body language and expression of emotion. There is often (but not always) decreased motivation to interact with others, and social interactions lack common reciprocal elements such as spontaneous seeking to share enjoyment or achievements, spontaneous interactive or parallel play, social or emotional reciprocity, and awareness of the mental states of others. For example, individuals with an ASD are less likely to engage in sharing or interactive play with caregivers or peers, may resist comforting from caregivers, or may

not notice or appropriately react to another person's happiness or distress. The social skill deficits that characterize ASD have been conceptualized as a deficit in "theory of mind," which refers to an ability to attribute mental states (e.g., beliefs, intents, desires) to self and others (Baron-Cohen, Leslie, & Frith, 1985). These deficits typically persist throughout the individual's life; however, while young children may have little interest in developing relationships with peers, older children and adolescents often have interest but lack opportunities due to poor social skills (Bauminger, Shulman, & Agam, 2003).

In addition to social deficits, communication deficits are present in autistic disorder and contribute to difficulty with social interaction and relationships. Both verbal and nonverbal communication is often affected, including receptive, expressive, and pragmatic aspects of language. In many cases, communication deficits begin in early childhood with a delay in language comprehension and a delay in, or absence of, spoken language. Individuals who develop verbal communication may exhibit difficulty with the ability to initiate or maintain conversation; exhibit abnormalities in pitch, intonation, rate or rhythm of speech (e.g., monotonous or contextually inappropriate tone of voice, halting speech); or display stereotyped, repetitive, or idiosyncratic use of language (e.g., repeating lyrics from songs). Additionally, conversational ability is affected by difficulty with the social uses of language, such as smooth integration of words and gestures; appropriate greetings; and understanding humor, sarcasm, and irony. While there is no language delay or lack of spoken language in Asperger's, people with Asperger's do typically present with abnormal nonverbal communication (American Psychiatric Association, 2000) and pragmatic language use. For example, individuals with Asperger's often have difficulty understanding the meaning of what is being said and

appropriately using language and back-and-forth conversation to meet needs and interact with others (Landa, 2000).

Repetitive, restrictive, and stereotyped patterns of behavior, interests, and activities are also a defining feature of ASD. Stereotyped motor mannerisms and/or self-stimulatory behaviors (e.g., hand-flapping or twisting, rocking) are common. In addition, individuals often present with excessively intense or focused preoccupations, a restricted range of interests (e.g., the scientific names of dinosaurs, radio station call letters), or preoccupation with parts of objects (e.g., repeatedly spinning wheels on a toy truck). Their preoccupations and restricted interests have led people to describe children with an ASD as “little professors” who may talk at length and in detail about special interests without noticing that their audience is exhibiting social cues associated with disinterest or boredom. Additionally, individuals with an ASD often present with inflexible adherence to nonfunctional routines or rituals (e.g., dressing in the same manner each morning), and with resistance to, and undue distress over, trivial changes (e.g., a detour on the way to school).

Associated Features

As noted above, in addition to the primary diagnostic symptoms of ASD, cognitive and intellectual functioning are impaired in an estimated 68% of individuals with an ASD, with cognitive presentation ranging from “high functioning autism” (HFA) and Asperger’s disorder, characterized by average to superior cognitive functioning, to “low functioning autism” (LFA), which is characterized by profoundly impaired intellectual functioning and verbal communication (Yeargin-Allsopp et al., 2003).

Samples of individuals with an ASD have also shown high rates of impulsivity, aggression, self-injurious behavior, or temper tantrums as well as increased risk for mood and affect problems, such as anxiety and depression (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). The relationship between the core ASD symptoms and these associated features is unclear. It has been suggested that, for higher functioning adolescents and adults, both insight into their condition and loneliness resulting from lack of social opportunities are causally related to depressive symptoms (American Psychiatric Association [DSM-IV-TR], 2000; Whitehouse, Durkin, & Jaquet, 2008). Some individuals also report unusual sensory responses, including hyper- or hyposensitivity to pain, touch, lights or odors, or fascination with certain sensory stimuli (e.g., Rogers & Ozonoff, 2005).

Developmental Course

ASD symptoms manifest before 3 years of age and the disorder follows a continuous course through childhood, adolescence, and adulthood. Most individuals achieve developmental gains in some areas to some degree (e.g., greater interest in socializing after entering school), but show continued deficits across multiple domains throughout life (Howlin, Goode, Hutton, & Rutter, 2004; Shattuck et al., 2007). Adolescence may be accompanied by either behavioral deterioration or improvement, with communication skills and overall intelligence considered the strongest prognostic indicators (Nordin & Gillberg, 1998; Szatmari, Bryson, Boyle, Streiner, & Duku, 2003). Data on adult outcomes are sparse and may underrepresent high functioning individuals who did not meet earlier diagnostic criteria or who experience less pervasive impairment.

However, available outcome data suggest that few individuals are able to live and work completely independently as adults, even within the high functioning population (Howlin, Goode, Hutton, & Rutter, 2004). In one of the largest outcome studies to date, Howlin and colleagues (2004) followed 68 adults with autism and an IQ above 50 and found that only one-third were employed, and one-third reported having a friendship. Furthermore, only 3 individuals lived independently, only 3 had married, and most people remained dependent on families and support services for income, supervision, and social support.

Although common developmental patterns have been identified, the overall presentation of ASD is idiosyncratic and heterogeneous, with symptoms ranging from relatively mild to profound. For example, social deficits can range from odd social approach and difficulty maintaining back-and-forth conversation, through reduced sharing of interests and emotions, to almost complete lack of social interest or initiation. Researchers have described these presentations as “active-but-odd,” and “aloof” subtypes (Borden & Ollendick, 1994; Waterhouse et al., 1996). Similarly, verbal communication deficits range from a delay in normal language to complete absence of verbal communication.

Sexuality in ASD

Growing interest in ASD research reflects the fact that it is no longer considered a rare disorder (Matson, 2007). One review identified 19,609 studies published on ASD between 1978 and 2008, with the annual number of studies increasing by 500-1000 each year since 2000 (Matson & LoVullo, 2009). Research emphasis has been placed on basic causes and psychological processes, diagnosis and early identification, and interventions

to remediate core deficits (Singh, Illes, Lazzeroni, & Hallmayer, 2009). One area that has been neglected is the sexuality of individuals with an ASD. Sexuality includes physical development, sexual behavior, and sexual or affective relationships, all occurring within the social context of relationships with family, peers, and sexual partners. A recent review identified only 13 peer-reviewed studies published on these topics between 1990 and 2010 (Gougeon, 2010), most of which were conducted with very small and poorly defined samples. The research that has been conducted on sexuality in ASD has focused on two main themes: (a) healthy versus inappropriate sexual interest and behavior, and (b) parent experiences with sexual development, including sexuality-related expectations and concerns. The research on each of these is reviewed below.

Overview of Sexuality and ASD

Though never empirically studied, there is a widely held misconception among parents and professionals that individuals with ASD lack interest in sexuality (Koller, 2000; Konstantareas & Lunskey, 1997; Ousley & Mesibov, 1991; Ruble & Dalrymple, 1993; Stokes & Kaur, 2005; Van Bourgondien, Reichle, & Palmer, 1997). However, research shows that most individuals with ASD display sexual interest and behavior. In one sample of 24 caregivers of young adult males with HFA, 96% of caregivers reported that the young men were interested in sexuality, 42% of young men were definitely known to masturbate, and 42% had expressed interest in an affectionate and/or sexual relationship (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007). Unfortunately, for people with ASD, interest in sexuality is less likely to translate into successful relationships. Ousley and Mesibov (1991) compared 21 adults with HFA to 20

adults with mild/moderate mental retardation (MR) and found that the two groups had a similar level of sexual interest, but people with MR had significantly more sexual experience than people with HFA. This might suggest that for people with ASD (even within the high functioning group), desire surpasses ability or opportunity to participate in intimate relationships to a greater extent than for people with other developmental disabilities. These findings may partially account for the sense of isolation, loneliness, and yearning for greater intimacy reported by some individuals with ASD (Bauminger, Shulman, & Agam, 2003; Muller, Schuler, & Yates, 2008; Ousley & Mesibov).

In addition to difficulty achieving positive sexual outcomes, youth with disabilities are more than twice as likely to be sexually abused or victimized compared to typically developing children (Spencer et al., 2005; Sullivan & Knutson, 2000). There is also concern that ASD symptoms (e.g., social skills deficits, cognitive impairment, and/or a tendency to develop intense and fixed interests) may lead to increased risk for inappropriate sexual behavior (ISB). Ruble and Dalrymple (1993) interviewed 100 parents of people with ASD (aged 9-38 years and characterized as verbal, minimally verbal, and nonverbal) about their child's sexual behavior and found that 65% of parents reported that their child touched their genitals in public, 23% masturbated in public, and 18% were reported to have touched another person inappropriately (i.e., touched breasts or genitals without consent). Similarly, in a survey of the 24 caregivers of institutionalized youth with HFA, several youth presented with "compulsive" masturbation that occurred several times per day and often in inappropriate situations (e.g., in the presence of others, whenever naked or bathing, when in bed in a shared room; Hellemans et al., 2007). Other research studies have reported the presence of

obsessive interest in sexuality, fascination with parts of the body (such as hair, bellies, or feet), and arousal in response to smells, electronic music, and objects in small samples of people with both ASD and ASD plus mental retardation (MR), but not MR alone (Hellemans et al., 2007; Hellemans et al., 2010). Collectively, these studies have been used to support the hypothesis that individuals with an ASD are at increased risk for displaying inappropriate sexual behavior due to ASD-specific deficits in understanding social norms and the known tendencies for individuals with an ASD to have restricted and repetitive interests. However, the generalizability of these studies is severely limited by small sample sizes, limited characterization of participants, and that they were conducted in institutional or group home settings, which introduce the confounds of both selection into such settings (i.e., higher incidence of problematic behavior) and potential influence of diverse sexuality-related policies in institutional settings (Van Bourgondien et al., 1997). In addition, none of these studies examined the relationship between specific ASD symptoms (e.g., various facets of social skill; perseverative, repetitive, or stereotyped behavior; sensory dysregulation) and sexual behavior. However, they do highlight the need for researchers and professionals to address the sexuality needs of the ASD population.

Sexuality Education

Sexuality education is recommended for youth with an ASD (Koller, 2000; Murphy & Elias, 2006; Travers & Tincani, 2010) in order to support the healthy sexual outcomes and prevent the negative outcomes outlined above. However, compared to the sexuality education literature for individuals with MR or other developmental disabilities,

research on effective sexuality education for individuals with an ASD is sparse (Sullivan & Caterino, 2008). There is, however, agreement on the importance of developmentally tailoring material and teaching techniques to the needs of each individual. For example, Travers and Tincani (2010) recommend that members of an Individualized Education Program (IEP) team (e.g., the individual, parents, advocates, and educational and healthcare professionals) make decisions about how and when to provide sexuality education for youth with ASD. Murphy and Elias (2006) have also recommended that pediatricians should guide parents in their efforts to provide effective sex education in addition to providing comprehensive sex education themselves. Unfortunately, there is evidence that the need for effective sexuality education in the ASD community is not being met.

Although little research has directly examined how many children and youth with ASD receive effective sexuality education, or what effective sexuality education entails in this population, some evidence suggests that they are less knowledgeable about sexuality and learn about sexuality and relationships from less credible sources. Comparing reports from 24 individuals with HFA and 46 typically developing individuals, Mehzabin and Stokes (2011) found that individuals with HFA reported learning about fewer topics and learning about sexuality by themselves or from friends and peers rather than from school or parents. However, other research found that, compared with typically developing youth, individuals with ASD learned less from peers, possibly reflecting their difficulty maintaining age-appropriate friendships (Stokes, Newton, & Kaur, 2007). Some individuals in these studies noted concern about basic sexual responses (e.g., erections), and stated that they would benefit from more sexuality

education (Mehzabin & Stokes, 2011). When asked, high functioning individuals with ASD reported that they were not learning relationship skills from parents, siblings, observation, media, sex education, or peers (Stokes et al., 2007). Thus, one of the most important ways to developmentally tailor sexuality education for individuals with ASD is to include information about the social aspects of relationships (Travers & Tincani, 2010).

The Sexuality Information and Education Council of the United States (SIECUS) and the American Academy of Pediatrics Council on Children with Disabilities both state the parents should be the primary sexuality educators for their children (Murphy & Elias, 2006; SIECUS, 2012). All parents must choose how and when to teach their children about sexuality, but little is known about how, when, and if parents of children with ASD teach their children about sexuality, or about barriers that may prevent them from doing so effectively. Parents of typically developing children have reported that they delay or neglect talking to their children about sex due to uncertainty about how or when to introduce topics, discomfort, and inadequate or inaccurate knowledge (Croft & Asmussen, 1992). Timing of discussion of sexuality topics may be even more complicated for parents of youth with ASD due to discrepancies between chronological age and developmental age (i.e., youth with ASD may act younger than other children their age). Research suggests that parents of typically developing children base their decisions about timing on their perception of whether their child has initiated sexual behavior. Research on typically developing adolescents (Beckett et al., 2010) shows that when adolescents are in the presexual stage, parent-child discussion revolves around developmental issues (i.e., puberty in boys and girls) and relationship topics like

choosing friends and why not to have sex. During the “precoital” stage (e.g., touching breasts and genitals, oral sex), parents begin to discuss sexual decision-making and sexually transmitted diseases (STDs). When parents suspect that their children are having intercourse, they focus discussion on STD and pregnancy prevention (e.g., recognizing symptoms of STDs, how to use a condom, choosing birth control). It is unclear whether similar patterns emerge in families managing ASD. Individuals with ASD are less likely to have sexual relationships than others, and thus parents may not know whether or when to introduce more concrete, prevention-related topics. Indeed, parents of youth with ASD have reported needing guidance to effectively provide sex education, and state that they are not receiving such guidance from schools, healthcare providers, or communities (Ballan, 2012; Nichols & Blakeley-Smith, 2010). Thus, individuals with ASD may not be receiving sexuality education, either formally or informally, possibly contributing to greater vulnerability to abuse, difficulty developing relationships, and higher risk for ISB (Hellemans et al., 2007; Hellemans et al., 2010; Ousley & Mesibov, 1991). In order to ensure that individuals with an ASD receive effective sexuality education, it is important to understand barriers and concerns that make parents less likely to provide sexuality education to youth with an ASD.

Parental Sexuality-related Expectations and Concerns

One possible reason why parents hesitate to provide sexuality education may be that they do not expect that their child will develop sexual relationships and thus do not expect that their child will need or benefit from sex education. Parental expectations play an important role in the relationship between family variables and a variety of child

outcomes. For example, parental expectations have been shown to mediate the relationship between child characteristics and enrollment in other educational programs (Alexander, Entwisle, & Bedinger, 1994; Davis-Kean, 2005; Mutua & Dimitrov, 2001; Neuenschwander, Vida, Garrett, & Eccles, 2007). For example, Mutua and Dimitrov (2001) surveyed the parents of 351 children with mild, moderate, and severe developmental disabilities and found that child characteristics (i.e., child gender and level of intellectual functioning) and parental expectation of positive future outcomes predicted whether parents enrolled their child in school.

Parental expectations for positive sexuality-related outcomes might also be expected to predict the quantity and quality of sexuality education provided by parents. Research on parental expectations for youth with ASD is sparse, but suggests that parents have more hope for success in education and civic life than for sexual relationships. For example, Ivey (2004) surveyed 25 caregivers of young children with mild, moderate, and severe ASD and asked them to rate the likelihood that their child would achieve personal, vocational, and community outcomes. On average, parents reported that the three least likely outcomes were “take care of parent in old age,” “have their own children,” and “get married.” However, the study did not examine the expectations for sexuality per se, nor did it examine the relationship between child factors (e.g., severity, specific ASD characteristics) and parental expectations. In another study, Ballan (2012) conducted semistructured qualitative interviews with 18 parents of relatively high functioning children with ASD (aged 6-13 years) to examine parental perspectives on parent-child communication about sexuality. Child characteristics (e.g., difficulty with reciprocal social interaction, lack of current social relationships, hypersensitivity to smells and

tastes) contributed to parents' collectively low expectations for the possibility of sexual relationships and to their attitudes about providing sexuality education. In this context, some parents described providing comprehensive sexuality education as irrelevant or cruel. However, they did endorse discussing modesty, puberty, and masturbation, perhaps based on the expectation that these topics would prove more relevant. Although not directly measured, the results suggested that perception of children's future opportunities had a large impact on parental choice of sexual topics to discuss. Unfortunately, if children do not receive comprehensive sexuality education, low parental expectations could become a self-fulfilling prophecy.

Research also suggests that parental expectations about a child's ability to have relationships in general are associated with the provision of sexuality education. Specifically, lower-functioning individuals may receive less sexuality education than those with greater verbal and intellectual ability, even though individuals with LFA may be at greater risk for exhibiting inappropriate sexual behavior. For example, Ruble and Dalrymple (1993) found that parents of children with higher verbal abilities were more likely to believe that their child would benefit from sex education, and thus were more likely to provide it. However, it was unclear whether this question referred to cognitive capacity to benefit, or general relevance of sex education due to limited opportunity for sexual relationships. In another study, parents who reported low expectations for their child to have healthy romantic relationships reported a sense of fatalism about sexuality education, and focused instead on preparing the individuals for repeated rejection (Ballan, 2012).

In addition to parental expectations for their child to develop romantic relationships, another barrier to providing effective sexuality education may be parental concerns about inappropriate sexual interest or behavior. Parents have reported concern that sexuality education or communication could lead to (rather than prevent or remediate) negative outcomes (i.e., ISB, sexual perseveration; Ballan, 2012). For example, Ballan found that many parents reported concern that education about basic sexual anatomy or behavior could lead to obsessive fixation on sexuality or on genitals, especially for children with preexisting fixations on mundane objects (e.g., trains). Parents of children who exhibited repetitive behaviors (e.g., hand-flapping, rocking) feared that education about masturbation might cause children to replace nonsexual self-stimulating behaviors with compulsive masturbation.

Another barrier that might discourage parents from providing sex education is that they may be unsure about how to provide developmentally tailored and effective sexuality education for their children. Studies of parents of youth with an ASD have reported that many parents feel the need for guidance on how to developmentally tailor sexuality education for their child (Nichols & Blakeley-Smith, 2010). They have also reported needing more effective teaching techniques. In one sample, some parents reported that despite seeking advice from special educators, developmental pediatricians, psychiatrists, and others, they still felt isolated, ill informed, and underprepared to address their child's sexuality. Research with parents of younger versus older children showed that topics they deemed appropriate changed over time, and that parents of older children expressed regret about lost opportunities to provide sex education (Ballan, 2012). Parents of younger children (aged 6-9 years) stated that sex education/

communication should begin in later elementary school and focus on body part awareness and modesty. In contrast, parents of older children (aged 10-13 years) indicated that sex education should begin in early elementary school and include sexual health information, puberty, and masturbation as “essential topics for younger children to learn.” Many of the parents of the older children indicated that delaying sex education had led to negative outcomes (i.e., inappropriate sexual behavior, lack of awareness of privacy). What is clear from these studies is that child characteristics affected parent expectations, which in turn affected parent attitudes toward how to developmentally tailor sexuality education.

Given the recommendation that parents be the primary sexuality educators for children, and the evidence that parents need guidance to provide developmentally tailored sexuality education and that youth with ASD are less knowledgeable about sexuality, more research is needed to understand what factors affect parent provision of sexuality education for youth with ASD.

The primary aims of the current study were to examine (a) whether overall ASD symptom severity predicted both parental romantic expectations and number of sexuality-related topics that parents reported having discussed with their children, and (b) whether parental romantic expectations were related to parental provision of sexuality education in terms of number of topics covered. Specifically, we predicted that (a) greater autism symptom severity would be associated with both lower parental romantic expectations and number of sexuality-related topics covered with children, and (b) parental romantic expectations would be related to the number of sexuality education topics covered with their child. The secondary aims of the current study were to examine whether specific ASD characteristics (i.e., social communication, social cognition, social motivation,

social awareness, and repetitive behavior) and parental fear of ISB predicted number of sexuality-related topics that parents reported having covered with their children.

METHOD

Participants

Parents of adolescents aged 12 – 18 years with Asperger’s disorder or high functioning autism were recruited to participate in an online survey of autism, sexuality, and sex education. One hundred thirty parents completed the survey. Of those parents, 120 provided enough data to be included in analyses (i.e., complete demographics and response to the remainder of the survey). To be eligible, the parent must have reported that the child was diagnosed with autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified, and that the diagnosis was conferred by a pediatrician, physician, psychiatrist, or clinical psychologist, as suggested by Nichols and Blakeley-Smith (2010). Exclusion criteria for this study included a parent-reported comorbid diagnosis of mental retardation (MR) or severe cognitive impairment, or parent-reported IQ under 85. Sixty-one participants who reported comorbid MR or reported IQ less than 85 were placed in a sample of low-functioning individuals. Participants were recruited online through local and national autism support groups and research networks.

Parent and child demographics are presented in Tables 1 and 2. Participating parents were predominantly Caucasian females (mothers), with a mean age of 47 years. Most participants were married or cohabiting (81.7%). The sample was highly educated,

with 70% of participants reporting that they had attained bachelor's degree, master's degree, or doctoral or professional degree. Last, the majority of participants (63.4%) described themselves as "somewhat" or "very" comfortable talking about sexuality. Children were predominantly Caucasian males, with a mean age of 14.5 years. All children lived at home with their parents, and most (65%) attended mainstream public school, with the remainder attending private, charter, and therapeutic schools. The majority of children in the sample were able to perform appropriate self-care skills either independently (40%) or with some prompting (45.8%); 14.1% of the sample could perform some or very basic self-care skills with supervision. Most children (89.9%) had begun to show signs of puberty, with 84% beginning puberty between the ages of 11 and 14. Most children (88.3%) fell within the "Moderate" or "Severe" range on the *Social Responsiveness Scale – 2nd edition* (SRS-2). SRS-2 Total Standard Scores ranged from 55 – 90, ($M = 77.63$, $SD = 6.82$, see Table 3).

Procedure

Links to the online survey were sent in emails to chapter heads of local and national autism support groups and research networks or posted directly on the websites or social media pages of autism support groups nationwide. Parents were invited to visit the online survey to participate in a study about autism, sexuality, and sexuality education. After reading a consent document, parents who agreed to participate completed the survey (Appendix A). The survey included demographic questions about children and parents and questions about the child's ASD (including cognitive, social, communication, and perseverative symptoms), child sexual behavior, parental

expectations, and parental provision of sexuality education. The survey also contained questions about parent attitudes, parental effectiveness in communicating with their children about sexuality, parental preparedness to manage children's sexual development, and parent concerns about inappropriate sexual behavior. After completing the survey, participants were routed to a separate page where they had the option of providing their contact information for the purposes of (a) receiving resources related to the topic of the survey, (b) receiving a summary of the results of the survey, and/or (c) participating in future research on the sexual development of children with ASD. All responses were confidential and anonymous; contact information was not connected with participants' survey responses. After completing the survey, parents were placed in a drawing for a chance to win one of ten \$40 gift cards.

Measures

Online Sexuality Survey

Parents completed a 50-item survey that included questions about parent and child demographics, as well as various potential parent and child factors. Parent factors included parent comfort discussing sexuality in general, parent ratings of their effectiveness communicating about sexuality with their children, and parent preparedness to manage their child's sexual development. Child factors included puberty status, time since puberty began, interest in romantic relationships or attraction to people of the same or other sex, and enrollment in school-based sex education. Additionally, the survey included the *Social Responsiveness Scale – 2nd edition*, a measure of ASD symptom severity, the Parental Expectations Inventory-Revised, a measure of parental romantic

expectations, and the Parent Sexuality Education Inventory, which measures parental provision of sex education.

Social Responsiveness Scale – 2nd edition (Parent Report) (SRS-2)

The SRS-2 (Constantino & Gruber, 2012) is a 65-item rating scale designed to measure the severity of autism spectrum symptoms with emphasis on the presence and extent of ASD-specific social impairment. For each of the items, deficits in specific areas of reciprocal social interaction are rated on a 4-point Likert-style scale. The scale also includes items measuring social communication and language, as well as restricted and stereotyped behaviors and interests. Reliability data for the SRS-2 indicate that test-retest is high ($\alpha = 0.90$). *T*-scores are standardized based on age and gender norms. The SRS-2 provides a total score and subscale scores, including subscales measuring Social Motivation, Social Cognition, Social Awareness, Social Communication, and Repetitive Behavior. Standardized scores (*T*-scores) of 76 or higher on the total scale are strongly associated with a diagnosis of autism or Asperger's disorder and indicate a severe interference in everyday social interactions. *T*-scores of 60 – 75 are typical for people with mild or “high functioning” ASD and suggest deficiencies in reciprocal social behavior with mild to moderate interference in everyday social interactions.

Parent Sexuality Education Inventory (PSEI)

The PSEI is a brief parent-report measure, designed for this study, assessing provision of sexuality education by parents for youth of all ages with an ASD. The scale includes 39 topics that parents may cover when teaching their children about sexuality.

Parents report whether and how they have taught their child about each topic, choosing from a list of teaching techniques common to ASD education. Both topics and techniques were adapted from Beckett et al. (2009), Koller (2000), Nichols and Blakeley-Smith (2010), Travers and Tincani (2010), and Wolfe, Condo, and Hardaway (2009). Topics include privacy, preventing sexual abuse, physical development of boys and girls, reproduction, preventing pregnancy and STDs, sexual decision-making, relationships, consent and coercion, and sexual health. Techniques include discussion, written and visual materials, video modeling, and skills-based training. If any teaching technique is used to cover a topic, a score of 1 is given for that topic; the total score is a measure of the number of topics covered (range = 0 – 39).

Parent Expectations Inventory - Revised (PEI-R)

The PEI-R is a 6-item parent-report measure modified from Mutua and Dimitrov (2001) to measure parental expectations for romantic and sexual relationships for children with ASD. Parents are asked to rate the likelihood of each outcome (e.g., go on dates, fall in love, have a healthy sexual relationship) on a 5-point Likert-type scale. Scores from all items can be summed to create a composite total score (range = 0 – 25), with a higher score indicating higher expectations.

Analytic Plan

Primary Aims

First, to test whether overall ASD severity (as measured by the SRS-2 Total Score) predicted parental romantic expectations (as measured by the PEI-R Score), a standard multiple linear regression was conducted with SRS-2 Total Score, Gender, and Age as the independent variables (IVs) and PEI-R Score as the dependent variable (DV). Next, to test whether overall ASD severity predicted the number of sexuality-related topics that parents covered with their children (as measured by the PSEI Score), a standard multiple regression was conducted with SRS-2 Total Score, Gender, and Age as the IVs and PSEI Score as the DV. To test whether parental romantic expectations (PEI-R Score) predicted number of sexuality-related topics covered (PSEI score), a simple linear regression was conducted with PEI-R Score as the IV and PSEI Score as the DV.

Secondary Aims

To explore whether specific ASD symptoms predicted provision of sex education, a series of standard multiple linear regressions was conducted with each of the SRS-2 subscale scores (Awareness, Cognition, Communication, and Motivational aspects of social behavior as well as Repetitive Behavior) as the IVs and number of sexuality related topics that parents covered with their children (as measured by the PSEI) as the DV. To determine whether parent rating of greater likelihood that sex education would result in ISB would predict coverage of fewer sexuality-related topics, a standard simple regression was conducted with parent likelihood rating (as measured by a 5-point Likert-type scale from “Not at all” to “Extremely” likely) as the IV and PSEI Score as the DV.

Table 1. Parent Demographic Variables ($N = 120^a$)

| | <i>N (%)</i> |
|---|----------------------------|
| Gender | |
| Female | 111(93.3) |
| Male | 8(6.7) |
| Ethnicity | |
| American Indian/Alaskan Native | 4 (3.3) |
| Asian | 2 (1.7) |
| Hispanic | 4 (3.3) |
| Multiracial | 3 (2.5) |
| White non-Hispanic | 107 (89.2) |
| Marital Status | |
| Single | 5 (4.2) |
| Long-term relationship/Cohabiting | 4 (3.4) |
| Married | 96 (80) |
| Divorced/Separated | 12 (10) |
| Widowed | 2 (1.7) |
| Locale | |
| Urban | 20 (16.9) |
| Suburban | 77 (65.3) |
| Rural | 21 (17.8) |
| Education | |
| Junior High | 1 (.8) |
| High School/GED | 5 (4.2) |
| Some college | 17 (14.3) |
| Associate degree/Vocational school | 12 (10.0) |
| Bachelor's degree | 42 (35.3) |
| Master's degree | 32 (26.9) |
| Professional or doctoral degree | 10 (8.4) |
| Current religiosity | |
| Not at all | 19 (16.0) |
| Not very | 36 (30.3) |
| Moderately | 41 (34.5) |
| Very | 23 (19.3) |
| Participation in ASD^b support group | |
| Yes, I actively participate | 66 (55.9) |
| No, I do not actively participate | 52 (44.1) |
| Median age (range) | 47 (33-63) |
| Median Income (range) | 90,000-99,999 (0-140,000+) |

^aNot all participants answered all questions (range = 114-120).

^bASD = autism spectrum disorder.

Table 2. Child Demographic Variables ($N = 120^a$)

| | <i>N (%)</i> |
|---|--------------|
| Gender | |
| Male | 104 (86.7) |
| Female | 16 (13.3) |
| Ethnicity | |
| American Indian/Alaskan Native | 1 (.8) |
| Asian | 2 (1.7) |
| Hispanic | 1 (.8) |
| Multiracial | 8 (6.7) |
| White non-Hispanic | 107 (89.9) |
| Diagnosis | |
| Asperger's syndrome | 72 (60.0) |
| Autism | 21 (17.5) |
| PDD ^b | 10 (8.3) |
| More than one selected | 17 (14.2) |
| Type of School | |
| Mainstream public school | 78 (65.0) |
| Private school | 13 (10.8) |
| Homeschooled | 12 (10.0) |
| Therapeutic school | 10 (8.3) |
| Charter school | 6 (5.0) |
| College | 1 (.8) |
| Median Age in Years (range) | 14 (12-18) |
| Median Age at Diagnosis in Years (range) | 8 (0-18) |

^aNot all participants answered all questions (range = 118-120).

^bPDD = Pervasive Developmental Disorder.

Table 3. Social Responsiveness Scale-2 Scores ($N = 120^a$)

| | T-Score Mean (SD) |
|--------------------------------|--------------------------|
| Total | 77.63 (9.18) |
| Awareness | 72.58 (10.39) |
| Cognition | 75.02 (9.72) |
| Communication | 76.63 (8.84) |
| Motivation | 71.71 (11.10) |
| Repetitive behavior | 75.60 (11.01) |
| Interpretive guidelines | N (%) |
| Below threshold | 4 (3.3) |
| Mild | 10 (8.3) |
| Moderate | 30 (25.0) |
| Severe | 76 (63.3) |

^aParticipants endorsed the degree to each question characterized their child on a 4-point Likert-type scale ("Not true" to "Almost always true").

RESULTS

Prior to conducting analyses, all variables were inspected to ensure normality and identify outliers. Parent (respondent) demographic information (i.e., gender, ethnicity, marital status, locale, education, income, religiosity) is provided in Table 1. Child characteristics are provided in Table 2. Parent responses to the PEI-R and PSEI are provided in Tables 4 and 5, respectively. PEI-R Scores ranged from 6 – 30 ($M = 20.04$, $SD = 5.22$). PSEI Score ranged from 0 – 39 ($M = 21.63$, $SD = 9.60$).

Results of Main Analyses

The primary aim of the current study was to examine the relationships between overall ASD severity (SRS-2 Total Score), parental romantic expectations (PEI-R Scores), and the number of sexuality-related topics parents reported having covered with their child (PSEI scores). Consistent with a priori hypotheses, results showed that, after controlling for Age ($B = -.206$, $SE = .252$, $p = .028$) and Gender ($B = -.078$, $SE = 1.356$, $p = .385$), higher SRS-2 Total Score predicted lower parental romantic expectations (PEI-R Scores; $B = -.303$, $SE = .053$, $p = .001$, see Table 6). The model that included SRS-2 Total, Age, and Gender accounted for 10.0% of the variance in PEI-R Scores. Contrary to a priori hypotheses, however, the model including Age ($B = .179$, $SE = .475$, $p = .062$), Gender ($B = .000$, $SE = 2.57$, $p = .997$), and SRS-2 Total Score ($B = .204$, $SE = .100$, $p =$

.034) did not predict PSEI Score ($F(3, 115) = 2.125, p = .101$). Similarly, PEI-R Score ($B = .143, SE = .168, p = .120$) did not predict PSEI Score (see Table 7).

Results of Secondary Analyses

The secondary aims of the current study were to examine whether specific SRS-2 subscale scores (e.g., Awareness, Cognition, Communication, and Motivational aspects of social behavior as well as Repetitive Behavior) and parent ratings of likelihood that sex education might lead to ISB, predicted the number of sexuality-related topics covered by parents (PSEI Score). Standard multiple regressions were conducted with Age and SRS-2 subscale score as the IVs and PSEI Score as the DV. Results are presented in Table 8 and show that after controlling for Age ($B = .161, SE = .456, p = .079$), the SRS-2 Cognition subscale score predicted PSEI Score ($B = .233, SE = .090, p = .012$), such that that higher social cognitive functioning predicted greater number of sexuality-related topics covered with children. However, the amount of variance accounted for by the SRS-2 Cognition subscale score was small ($R^2 = .067, F(2, 118) = 4.163, p = .018$). The SRS-2 Social Motivation subscale score also predicted PSEI Score ($B = .244, SE = .078, p = .008$) after controlling for Age ($B = .159, SE = .453, p = .082$), with higher social motivation predicting greater number of sexuality-related topics covered with children. Again, the amount of variance accounted for by the SRS-2 Motivation subscale score was small ($R^2 = .072, F(2, 118) = 4.530, p = .013$). The three remaining SRS-2 subscale scores, Awareness ($B = .162, SE = .087, p = .090$), Communication ($B = .157, SE = .102, p = .099$), and Repetitive Behavior ($B = .110, SE = .082, p = .248$), did not significantly

predict PSEI Score. Parent ratings of the likelihood that sex education would cause ISB also did not predict PSEI Score ($B = .014$, $SE = 1.055$, $p = .880$).

Exploratory Analyses

Given that neither ASD symptom severity nor parental romantic expectations or concerns about ISB predicted a substantial amount of variance in the number of sexuality-related topics covered by parents, exploratory analyses were conducted to examine other relevant child and parent factors related to parental provision of sexuality education.

First, to determine whether child characteristics (e.g., interest in sex, participation in school-based sex education) were related to parental provision of sex education, a series of univariate analysis of variance (ANOVA) tests, independent sample t -tests, and correlation analyses were conducted. Results showed that for children who had shown signs of puberty, time since puberty began (age at beginning of puberty subtracted from current age) was not correlated with PSEI Score ($r = .066$, $p = .505$). Additionally, the number of sexuality-related topics that parents covered did not differ based on whether children expressed interest in a romantic relationship ($F(2, 116) = 2.033$, $p = .136$), whether they had expressed attraction to someone of the same or other sex ($F(2, 116) = 1.674$, $p = .192$), or whether they had participated in school-based sexuality education ($F(1, 116) = 1.151$, $p = .286$).

Second, to examine whether parent factors (i.e., gender, age, marital status, efficacy, comfort, and preparedness) were related to provision of sex education, a series of multiple linear regressions were conducted. A multiple linear regression showed that

parent gender ($B = -.056$, $SE = 3.833$, $p = .555$) and age ($B = -.048$, $SE = .145$, $p = .613$) did not predict PSEI score. Similarly, a t -test for marital status (with responses collapsed into two categories: those in a long-term relationship, cohabiting, or married; and those who were single, divorced or widowed) showed no difference in mean PSEI score ($t(117) = -.698$, $p = .487$). To examine whether parent-reported efficacy in communicating with children about sex, preparedness to manage children's sexual development, and comfort talking about sex in general were related to parental provision of sex education, a multiple linear regression analysis was conducted with these variables as the IVs and PSEI Score as the DV. The model accounted for 30.2% of the variance in PSEI Score ($R^2 = .302$, $F(3, 114) = 16.448$, $p = .000$), with efficacy ($B = .328$, $SE = .978$, $p = .003$) and preparedness ($B = .278$, $SE = .995$, $p = .010$) significantly predicting PSEI Score, showing that greater perception of parental efficacy and preparedness predicted a greater number of sexuality-related topics covered with children. Parent comfort talking about sex in general did not significantly predict PSEI Score ($B = -.030$, $SE = .568$, $p = .714$).

Table 4. Parent Expectations for Child Romantic Future ($N = 120^a$)

| | Percentages | | | | |
|--|---------------|-------------------|-----------------|-------------|-------------|
| | Very unlikely | Somewhat unlikely | Slightly likely | Likely | Very likely |
| My child will... | | | | | |
| ...experience sexual desire for other people | 0.8 | 7.6 | 19.5 | 37.3 | 34.7 |
| ...fall in love | 4.2 | 14.3 | 26.1 | 41.2 | 14.3 |
| ...get married or find a life partner | 5.1 | 18.8 | 30.8 | 35 | 10.3 |
| ...go on dates | 5.9 | 17.6 | 34.5 | 30.3 | 11.8 |
| ...have a healthy sexual relationship | 6.7 | 20.2 | 34.5 | 31.1 | 7.6 |
| ...have children | 9.2 | 20.2 | 33.6 | 30.3 | 6.7 |

^aNot all participants answered all questions (range = 117-120).

Table 5. Sexuality Education Topics Covered by Parents ($N = 120^{a,b}$)

| | Percentages | |
|---|---------------|-------------|
| | Did Not Cover | Covered |
| Privacy (e.g., knocking before entering rooms, undressing in private) | 1.7 | 98.3 |
| Private body parts | 2.5 | 97.5 |
| What kinds of touch are okay/not okay | 5.0 | 95.0 |
| Public and private discussion topics | 7.6 | 92.4 |
| Hygiene (e.g., washing genitals) | 7.6 | 92.4 |
| How boys' bodies change physically as they grow up | 9.2 | 90.8 |
| What qualities are important in choosing close friends | 15.1 | 85.7 |
| Homosexuality/people being gay | 17.8 | 82.2 |
| How women get pregnant and have babies | 24.6 | 75.4 |
| How to report sexual abuse | 29.4 | 70.6 |
| Family types and roles | 30.3 | 69.7 |
| How girls' bodies change physically as they grow up | 33.1 | 68.6 |
| Parenting | 34.5 | 65.5 |
| Menstruation (menstrual periods) | 36.1 | 65.3 |
| Consequences of getting pregnant/getting someone pregnant | 35.6 | 64.4 |
| Dating and marriage | 36.1 | 63.9 |
| Reasons why your child should not have sex | 39.0 | 61.0 |
| Masturbation (e.g., is it okay? When and where it is appropriate) | 40.3 | 59.7 |
| Sexual slang terms that people might use | 47.1 | 52.9 |
| Wet dreams | 49.2 | 51.7 |
| How people can prevent getting sexually transmitted diseases (STDS) | 50.4 | 49.6 |
| How your child will make decisions about whether to have sex | 51.7 | 48.3 |
| How to say no if someone wants to have sex and your child doesn't want to | 52.1 | 47.9 |
| How to ask someone out on a date | 56.3 | 44.5 |
| Sexuality as a positive aspect of self | 57.1 | 42.9 |
| How well birth control can prevent pregnancy | 57.3 | 42.7 |
| How your child will know whether s/he is in love | 57.6 | 42.4 |
| How to deal with romantic rejection | 58.0 | 42.0 |
| How well condoms prevent STDs | 58.5 | 41.5 |
| The importance of not pressuring other people to have sex | 59.7 | 40.3 |
| Reasons why people like to have sex | 62.2 | 37.8 |

Table 5 Continued. Sexuality Education Topics Covered by

| | Percentages | |
|--|--------------------|---------|
| | Did Not Cover | Covered |
| The necessity of regular exams by themselves and with doctors (e.g., Pap, breast and testes exams) | 63.6 | 36.4 |
| Sexual activities other than intercourse | 71.4 | 28.6 |
| Symptoms of STDs | 73.1 | 26.9 |
| Any sexual or romantic differences or difficulties that might result from autism | 76.3 | 23.7 |
| How to use a condom | 79.5 | 20.5 |
| What to do if a partner doesn't want to use a condom | 82.2 | 17.8 |
| What it feels like to have sex | 81.5 | 18.5 |
| How to choose a method of birth control | 85.6 | 14.4 |

^aNot all participants answered all questions (range = 117-120).

^bSTDs = Sexually transmitted diseases

Table 6. Predictors of Parental Expectations Inventory-Revised Score

| | <i>F</i> | <i>B</i> | <i>SE B</i> | <i>Beta</i> | <i>p</i> | <i>Part</i> |
|-----------------------|----------|----------|-------------|-------------|----------|-------------|
| SRS-2 Total Score | 4.238* | -0.172 | 0.053 | -0.303 | 0.001 | -0.289 |
| Gender | -- | -1.184 | 1.356 | -0.078 | 0.385 | -0.077 |
| Age | -- | -0.562 | 0.252 | -0.206 | 0.028 | -0.197 |
| <i>R</i> ² | 0.100 | | | | | |

Note: * = $p < .05$ **Table 7.** Predictors of Parental Sexuality Education Inventory Score

| | <i>F</i> | <i>B</i> | <i>SE B</i> | <i>Beta</i> | <i>p</i> | <i>Part</i> |
|-----------------------|----------|----------|-------------|-------------|----------|-------------|
| SRS-2 Total Score | 2.125 | 0.214 | 0.100 | 0.204 | 0.034 | 0.195 |
| Gender | -- | -0.009 | 2.557 | -0.000 | 0.997 | 0.000 |
| Age | -- | 0.895 | 0.475 | 0.179 | 0.062 | 0.171 |
| <i>R</i> ² | 0.053 | | | | | |

Note: * = $p < .05$ **Table 8.** SRS-2 Subscale Score Predictors of PSEI Score with Age Included in Model

| | <i>F</i> | <i>B</i> | <i>SE B</i> | <i>Beta</i> | <i>p</i> | <i>R</i> ² |
|----------------------|----------|----------|-------------|-------------|----------|-----------------------|
| Social Cognition | 4.163* | 0.230 | 0.090 | 0.233 | 0.012 | 0.067 |
| Social Motivation | 4.530* | 0.211 | 0.078 | 0.244 | 0.008 | 0.072 |
| Social Awareness | 2.321 | 0.149 | 0.087 | 0.162 | 0.090 | -- |
| Social Communication | 2.246 | 0.170 | 0.102 | 0.157 | 0.099 | -- |
| Repetitive Behavior | 1.522 | 0.096 | 0.082 | 0.110 | 0.248 | -- |

Note: * = $p < .05$

DISCUSSION

Sexuality education is important for fostering healthy relationships and promoting healthy sexuality for all youth, including those with ASD. For parents of youth with ASD, however, providing sexuality education is complicated by the unique symptoms and developmental deficits that characterize the child's condition (e.g., cognitive and/or social deficits, restricted and repetitive interests and fixations). Recent research suggests that many children with ASD lack knowledge of basic sexuality-related topics and are not receiving effective sexuality education from their parents or other educators. To date, there have been few empirical studies examining factors related to parental provision of sex education in ASD. However, a small body of qualitative research has suggested that both ASD severity and parental expectations play a primary role in whether parents provide sex education to children with ASD and what topics they cover. Specifically, it has been suggested that because of their child's symptoms, parents of children with ASD have uncertain expectations about whether their child will fall in love, marry, or have a sexual relationship and this, in turn, affects whether parents provide comprehensive sex education to their child (Ballan, 2012; Ruble & Dalrymple, 1993). It has also been suggested that parents whose children show repetitive and restricted interests are hesitant to discuss sex with their child out of fear that discussing these topics will result in

inappropriate sexual behavior (ISB). The purpose of the current study was to examine factors related to parental provision of sex education in a sample of parents with a child with high-functioning ASD.

The first aim of the current study was to examine the relationships among overall ASD severity, parental romantic expectations, and the number of sexuality-related topics parents reported having covered with their child. Based on previous research, we predicted that higher levels of overall ASD severity would be related to decreased romantic expectations, and our results confirmed this hypothesis. We also predicted that both overall ASD severity and parental romantic expectations would predict fewer sexuality-related topics covered. However, contrary to expectations, neither of these variables was related to the number of sexuality-related topics that parents reported having covered with their child.

There are several possible explanations for these findings. First, finding that parental expectations did not predict the number of sexuality-related topics covered might suggest that romantic expectations do not play a significant role in parental provision of sexuality education. Although previous research within the developmental disabilities literature has shown that parental expectations in other areas (e.g., civic or vocational expectations) predict whether parents provide relevant educational opportunities to their child, romantic expectations may have less of an impact on the extent to which parents provide sex education. Alternatively, the outcome measure used in the current study may not have captured important elements of sexuality education that are relevant to parental expectations. The primary outcome variable in the current study was the overall number of sexuality related topics that parents reported having covered with their child at one

particular point in time. Sexuality education, however, can perhaps best be viewed as an ongoing process. As such, whereas the outcome measure used in this study captures one indicator of parental provision of sexuality education, it may not adequately capture many of the important nuances of how, when, and what parents teach their child about sexuality over the course of adolescence. It is possible that parental romantic expectations do not influence the *overall number* of sexuality-related topics that parents cover with their child, but rather they may influence whether, when, and how they cover *specific* topics. For example, it is possible that parental romantic expectations (e.g., whether they expect that their child will fall in love, marry, or have a healthy sexual relationship) might differentially predict whether parents cover specific topics such as sexual decision-making versus basic sexual anatomy and privacy, which may be topics that most parents cover regardless of their romantic expectations for the child or their child's ASD severity. In addition, it may be that parental romantic expectations are important (in term of whether they provide sexuality education) but that the expectation and sexuality topics measured did not correspond in a meaningful way. For example, parents may deem some sexuality education topics (e.g., symptoms of STDs) irrelevant to the romantic expectations that were measured (e.g., that their child would marry and have children). Future research is needed to examine whether *specific* parental expectations affect the provision of *specific* aspects of sexuality education using more comprehensive measures that capture other dimensions of the sexuality education process, including whether, when, and how parents teach children about specific topics.

Another interesting finding from the current study was that although overall ASD severity did not predict the number of topics that parents discussed with their child,

specific ASD symptoms explained a small but significant amount of variance in the number of topics covered. Specifically, parents who rated their child higher on measures of social motivation and social cognition covered a greater number of sexuality-related topics with their child, suggesting that specific ASD characteristics (especially social deficits) may be better predictors of whether parents provide sex education than overall ASD severity. One explanation is that their greater social engagement and social skills resulted in these youth initiating more frequent or broad-ranging discussion about sexuality with their parents (either directly, through questions, or indirectly through their actions and experiences). The current study did not differentiate between child- and parent-initiated discussions about sexuality-related topics nor did it measure why parents chose to discuss some topics versus others. An alternative explanation is that these social characteristics may directly influence whether parents think that it is important or even advisable to teach their children about sexuality. Parents of children who show less social motivation may believe that their children are not interested in sexual relationships and thus would not benefit from sex education. Parents of children with more severe social cognitive deficits may worry that providing sex education could lead to inappropriate sexual behavior (ISB) or other problems (e.g., the emotional consequences of repeated rejection) because their child struggles to interpret social cues. In addition, it is possible that parents feel less certain about how to address certain sexuality topics with their child because of his/her social deficits. Last, parents of children with high social cognition and motivation may be more inclined to cover specific sexuality-related topics, such as relationship issues. If this is the case, it is possible that children who appear less socially motivated and adept may receive less information about relational aspects of sexuality,

which could confound their difficulties in this area. Future research is needed to examine the relationship between ASD symptom severity and coverage of specific sex education topics.

Previous research has also suggested that parents whose children show repetitive and restricted interests are hesitant to discuss sexuality-related topics with their child out of fear that discussing these topics will result in inappropriate sexual behavior (ISB). For example, Ballan (2012) found that parents reported concern that education about basic sexual anatomy or behavior could lead to obsessive fixation on sexuality or on genitals, especially for children with preexisting fixations on mundane objects (e.g., trains). In addition, this same study found that parents of children who exhibited repetitive behaviors (e.g., hand-flapping, rocking) feared that education about masturbation might cause children to replace nonsexual self-stimulating behaviors with compulsive masturbation. Interestingly, in the current study, scores on the restricted and repetitive interests subscale of the SRS-2 and parental ratings of the likelihood of sex education leading to ISB did not predict the number of sexuality-related topics that parents covered with their child. As previous qualitative research did not report the number of parents who reported this concern, it is possible that very few parents worry that sex education will result in ISB. In the present study, 11% of parents stated that it was “Somewhat,” “Moderately, or “Very” likely that sex education would lead to ISB. On the other hand, the prospect of an increase in some inappropriate sexual behaviors (e.g., asking inappropriate questions in public, unusually frequent masturbation) may not deter parents from providing sex education, especially if they believe that it will lead to positive outcomes such as sexual abuse prevention or healthy relationships.

Given that overall ASD severity and parental expectations did not predict the number of sex education topics covered, and specific symptom dimensions explained only a small amount of variance, the current study also attempted to identify additional parent and child factors related to parental provision of sex education, including parent gender, age, and marital status, and child puberty status, interest in sex, and participation in school-based sex education. The only factors that predicted the number of sexuality-related topics that parents reported covering with their child were parental efficacy in communicating with children about sexuality and overall parental preparedness to manage child sexual development. This is perhaps not surprising considering that in general, people who are confident in their ability to effectively perform a behavior and who associate positive outcomes with that behavior are more likely to engage in the behavior than are individuals who are not confident in their efficacy or who anticipate negative outcomes (Bandura, 1997). Consistent with this finding, research with parents of typically developing youth has found that mothers with greater self-efficacy regarding their ability to communicate with their children about sexuality are more likely to provide sex education to their child (DiIorio et al., 2000). Future research is needed to examine interventions that increase parental efficacy, as this may lead to parents providing more effective or more comprehensive sex education.

Several limitations of the current study warrant mention. First, parents in this sample were not compared to a typically developing control group. As such, we could not determine whether either parental romantic expectations or the number of sexuality-related topics that parents covered differed for this sample versus parents of typically developing children. Most parents in the current sample reported that they covered basic

sexuality-related topics, such as puberty, abstinence, reproduction, and dating and marriage, but failed to cover other topics such as unwanted pregnancy and STD prevention or sexual decision-making. This pattern may reflect the topics that most parents (regardless of ASD diagnosis) cover when delivering sex education to their children. Second, this sample included only youth on the high functioning end of the autism spectrum (i.e., IQ in the average or above range). It is possible that the relationships between overall ASD symptom severity, specific symptom severity, and parental provision of sex education differ for parents of low functioning youth with ASD. Third, as noted above, in the current study sex education was defined as the number of topics that parents self-reported having covered with their child. This measure does not capture important elements of sexuality education, including how often the topics were discussed, when the discussion was initiated, the depth of instruction, etc. Thus, the current study did not determine whether parents delivered accurate information about sexuality, whether their delivery was effective, or whether their messages were positive or negative in tone. This will be important information for those developing home-based sexuality interventions for families of children with ASD. Last, the current study was based on parent self-report, both current and retrospective, and some inaccuracies may exist. It will be important for future research to compare parent and child reports and to obtain some objective measure of child sexuality knowledge.

It is important to note that Internet-based surveys have inherent limitations, especially those studies concerning sexuality. Previous research comparing Internet-based sexuality research to population-based research indicates that participants in Internet-based research are likely to be younger, to live in a major city, and to be better

educated (Ross, Mansson, Daneback, Cooper, & Tikkanen, 2005). In addition, they are more likely to be attracted to the same sex, and to have had a higher number of sex partners in the past year. Thus, parents who choose to participate in such studies may not be representative of the general population. Additionally, the demographics of the current sample were somewhat restricted and may not reflect the broader population of parents of children with ASD. For example, participants were predominantly White, married mothers who were well educated (over one-third of participants reported that they had obtained a master's degree or higher). In addition, the modal personal income was \$140,000 or more per year, the highest income bracket included in the survey. Previous literature indicates that participants with higher education and income levels report more communication about sexuality with their children (DiIorio, Pluhar, & Belcher, 2003), so it is possible that the results of the current study may overestimate the extent to which parents cover sex-related topics with their children. Additionally, although only half of participants were actively involved in an ASD support group or organization, all participants were recruited through some connection to such support groups, suggesting that they may have had more access to resources and support than parents of children with ASD in the general population and may have made sex education a priority based on access to information about the course of ASD or conversations with other parents. Although none of the demographic or support variables were related to the primary outcome measure, the results should be interpreted with these sample limitations in mind. Finally, the current study may have oversampled individuals who were comfortable talking about sexuality. However, it is noteworthy that within the current sample, parents'

self-reported comfort in talking about sexuality was not associated with any of the main outcome variables, including number of sexuality-related topics covered with children.

Despite these limitations, this study was the first to directly examine factors related to parental provision of sexuality education to adolescents with ASD. Because research on ASD, sexuality, and sexuality education is in its early stages, it is not possible to determine whether the results of the present study are conclusive. ASD and sexuality is an area of growing interest and concern for researchers and professionals, and each study represents a step toward greater understanding. The present study contributed to the literature by addressing methodological limitations of previous research. This study used quantitative methods to replicate the findings of qualitative research, collected one of the largest samples to date in studies of ASD and sexuality, and constrained analyses to high-functioning youth with ASD, eliminating confounding child characteristics. Future research can build upon the results of this study. Our analyses suggest that, rather than child characteristics, parent self-efficacy and preparedness regarding children's sexual development may better predict whether parents provide comprehensive sex education for youth with ASD. Should this prove to be a consistent finding, it would be worthwhile to shift the focus on research from parental romantic expectations to effective sexuality-related communication and preparedness. The evidence is mixed, but research suggests that parent communication about sexuality and reinforcement of knowledge and values affects adolescents' sexual behavior, particularly where sexual health and disease prevention is concerned (DiIorio et al., 2003). Youth with ASD in particular need information to be presented repeatedly, and parents may be more likely to serve in this capacity if they perceive themselves as being effective sexuality teachers. If research on

parent knowledge, confidence, and self-efficacy is pursued in the future, this information could lead to interventions to support parents in communicating with children about sexuality (e.g., Nichols & Blakeley-Smith, 2010).

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